Changes in the Prevalence and Incidence of Autism Spectrum Disorder Across Multiple Birth Cohorts in Utah, USA

Julia Hood, Ph.D., BCBA-D, NCSP, Blessing Ofori-Atta, M.S., Amanda V. Bakian, Ph.D., & Deborah Bilder, M.D.
University of Utah and the Utah Registry for Autism and Developmental Disabilities

Background

There is significant interest in understanding reasons for the rapid increase in measured ASD prevalence over the last few decades. In the U.S., the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network is the primary source for ASD prevalence estimates. These estimates are critical to assess and plan for needed care, funding, and community resources. While ASD prevalence was previously thought to peak at age 8, previous research demonstrates only two-thirds of people with ASD are identified by this age.[1] A similar study measuring the cumulative incidence of autism in Denmark found that it does not plateau at 8 years old, but continues to increase into adolescence.[2] Monitoring change in ASD overtime within multiple birth cohorts (BC) through early adulthood may provide more accurate estimates of ASD prevalence than estimates based cross-sectionally on 8-year-olds.

Methodology

Birth cohorts from 1994-2014 were separated into five groups each combining four BC's (e.g., 1994-1997, 1998-2001). ASD identification in the birth cohorts was based on International Classification of Diseases, ninth or tenth revision codes for autism and/or an autism special education eligibility. ASD ascertainment was conducted statewide from birth through 2018; age at earliest identification was identified. The population size from birth through 2018 was identified by age and sex from the National Center for Health Statistics' bridged-race postcensal population estimates using the latest vintages. The cumulative incidence was measured as the number of children identified with ASD at or before each year of age divided by the total population at or before each year of age. Prevalence in 2018 was estimated using the number of individuals identified with ASD in each group of BC's divided by the size of the population in 2018.

References

[1] Scheldrick RC, Maye MP, Carter AS. Age at first identification of autism spectrum disorder: an analysis of two US Surveys. *J Am AcadChild AdolescPsychiatry*. 2017;56(4):313-320.

[2] Dalsgaard, S., Thorsteinsson, E., Trabjerg, B. B., Schullehner, J., Plana-Ripoll, O., Brikell, I., ... & Pedersen, C. B. (2020). Incidence rates and cumulative incidences of the full spectrum of diagnosed mental disorders in childhood and adolescence. *JAMA psychiatry*, *77*(2), 155-164.

Figure 1: Cumulative incidence of ASD per 1,000 persons, overall and by sex separated for each birth cohort in Utah from birth to 2018.

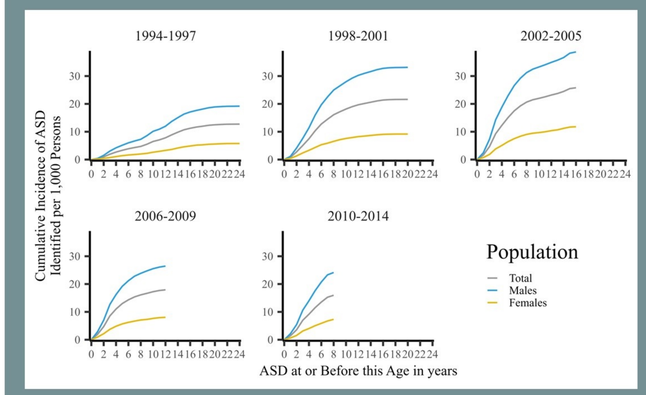

Figure 2: Cumulative incidence of ASD per 1,000 persons combined for each birth cohort overall and by sex in Utah from birth to 2018.

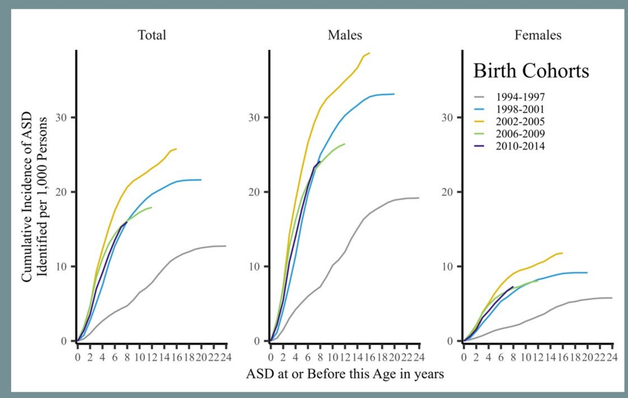

Figure 3: Prevalence of ASD per 1,000 persons by birth cohort, overall and by sex in Utah in 2018

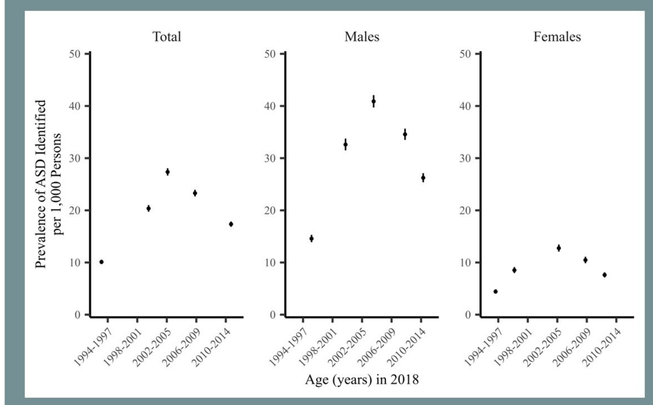

Table 1: Prevalence of ASD per 1,000 persons by birth cohort in Utah in 2018.

	ASD			Population Estimates in 2018			Prevalence Estimate		
Birth Cohorts	Overall	Males	Females	Overall	Males	Females	Overall	Males	Females
1994 - 1997	2121	1641	468	213329	111774	101555	9.94	14.68	4.61
1998 - 2001	3922	3083	811	191957	95096	96861	20.43	32.42	8.37
2002 - 2005	5685	4358	1276	208398	106748	101650	27.28	40.83	12.55
2006 - 2009	4979	3807	1086	214356	110397	103959	23.23	34.48	10.45
2010 - 2014	4476	3493	977	258630	132709	125921	17.31	26.32	7.76

Results

The cumulative incidence (CI) of ASD by 2018 was lowest in the 1994-1997 BCs (CI = 12.74), higher in the 1998-2001 BCs (CI=21.63), peaked in the 2002-2005 BCs (CI = 25.79), and then declined for the 2006-2009 (CI = 17.93) and 2010-2014 BCs (CI = 15.98 Figure 1). In all birth cohorts that included ages greater than 8 years in 2018, the cumulative incidence of ASD was significantly higher for each BC's age in 2018 than at age 8 (1994-1997 BC's age in 2018 vs age 8: 12.74 vs 4.72; 1998-2001 BC's age in 2018 vs age 8: 21.63 vs. 16.1; 2002-2005 BC's : 25.79 vs. 20.64; 2006-2010 BC's age in 2018 vs age 8 : 17.93 vs. 16.12). The cumulative incidence at age 4 was highest among the 2002-2005 BCs (Figure 2). ASD prevalence in 2018 in the 1994-1997 BC's was significantly lower than the ASD prevalence in the other BCs with a peak in prevalence measured in the 2002- 2005 BCs followed by a decline in the remaining BCs (1994-1997 BCs = 9.94/1000; 1998-2001 BCs = 20.43/1000; 2002-2005 BC = 27.27/1000; 2006-2009 BC = 23.23/1000; 2010-2014 BCs= 17.31/1000). A plateau in ASD cumulative incidence appears to begin at approximately age 16 in the 1994-2005 BC's.

Conclusion

Utah's identification of children with ASD in health and school settings continues into adolescence for birth cohorts from 1994 through 2005. Identification also continues past age 8 for all birth cohorts older than age 8 in 2018. The cumulative incidence appears to plateau after age 16, which may suggest that Utah's peak incidence occurs much later than traditionally thought. The increase of prevalence between the 1994-1997 and 2010-2014 birth cohorts suggests a corresponding two-fold increase in diagnostic and intervention service needs, funding, and community resources over the past 20 years. In addition, the decrease in prevalence in 2018 for the 2006-2009 and 2010-2014 birth cohorts suggest that we are still not adequately identifying those with ASD by age 8 and even into adolescence. Further, our finding that peak CI occurred among 4-year-olds from the 2002-2005 BCs suggests a lack of improvement in efforts in recent years to decrease age at first identification in Utah. ASD service planning in Utah, however, is currently informed by single age, single birth cohort studies and may not correspond with population need.

Utah Registry of Autism and Developmental Disabilities

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY
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